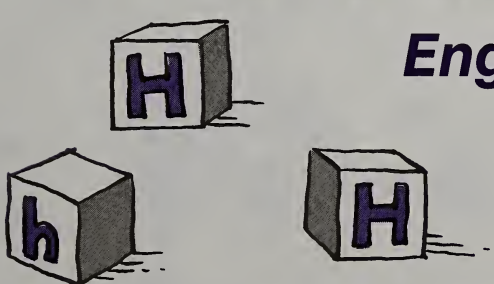
Thalassemia Among Asians

English



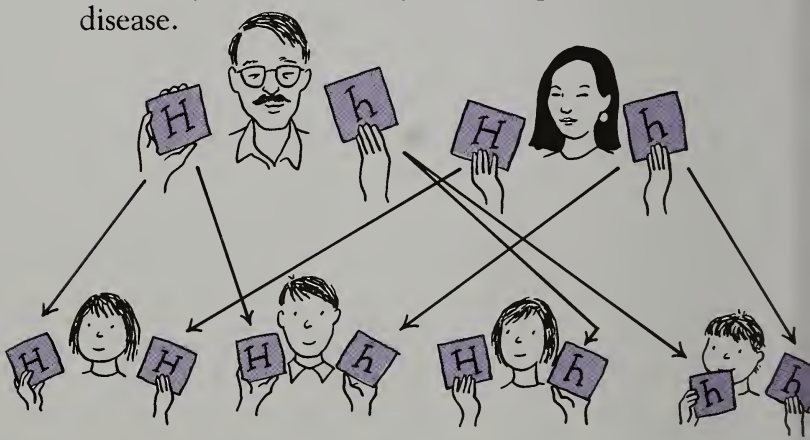
AAPCHO
Association of Asian Pacific Community Health Organizations

What is Thalassemia?

Thalassemia is an inherited blood disorder. People who have thalassemia disease are not able to make enough hemoglobin in their red blood cells. Hemoglobin is the part of a red blood cell which picks up oxygen from the lungs and carries it to all parts of the body. All the tissues of the body need oxygen. Without enough hemoglobin in the red blood cells, oxygen cannot get to all parts of the body. Tissues are starved for oxygen and cannot function properly.

How do You Get Thalassemia?

You can only get Thalassemia by inheriting the condition. You cannot catch it from someone else. We all inherit tiny building blocks called genes from our parents. These genes determine what we look like. They control the color of our eyes and hair and account for the resemblance of family members to each other even through several generations. In addition to physical characteristics, genes are also responsible for many diseases. That is why some diseases run in families. The genes that make hemoglobin are also passed on from parents to their children, and carry with them any defects, problems or disease.



Who Inherits Thalassemia?

Anyone whose parents carry the gene can inherit thalassemia. The disease is most common in people from the Mediterranean (Greece and

Italy), Middle East (Iran, Israel and Turkey), Africa, Asia (China, India, Thailand and the Philippines) and Southeast Asia. Out of all of these groups of people, Thalassemia is most prevalent among Southeast Asians.

Thalassemia Disease

There are two main types of Thalassemia Disease Alpha Thalassemia and Beta Thalassemia.

Alpha Thalassemia

Alpha thalassemia major is very severe and in almost all cases results in hydrops fetalis (stillbirth or newborn death) and maternal problems. The fetus is already affected in the womb and dies at or soon after birth.

Another alpha thalassemia disease is called Hemoglobin H Disease. It causes the body to make less red blood cells which can result in serious health problems.

Beta Thalasemia

Beta thalassemia major (also called Cooley's disease) is not usually evident at birth but symptoms generally appear after the first three months of the baby's life. The baby then starts to develop a paleness of the skin, poor appetite, irritability, and failure to grow. If left undiagnosed, the child's bone structure changes and the child becomes increasingly anemic (not having enough red blood cells) and the child may even die if not treated immediately. The child with beta thalas-

semia major must have blood transfusions every month to survive.

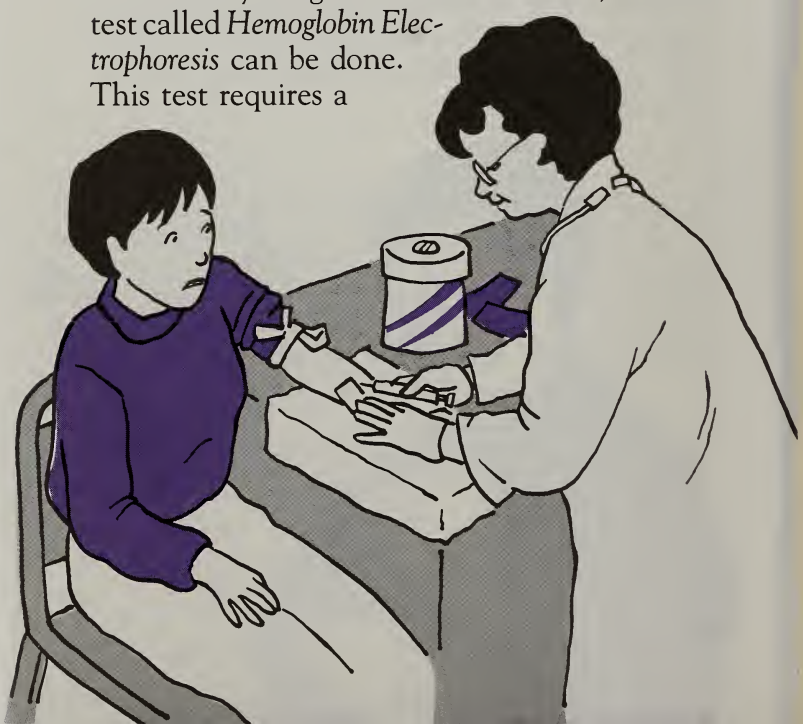
Other forms of beta thalassemia disease are Thalassemia Intermedia and Hemoglobin E-Beta Thalassemia. They are the less severe forms of thalassemia. However, they still cause the body to not make enough red blood cells and the person tires easily, grows slowly, catches frequent infections and may develop other medical problems. Furthermore, many Hemoglobin E-Beta Thalassemia patients may require regular blood transfusions.

Thalassemia Trait

Alpha and Beta thalassemia traits are the most common forms of thalassemia. Traits are not the disease. A thalassemia trait gene may cause some slight anemia in the person who inherited the gene, but there would be no major health problems created by this gene. Knowing that you and your spouse do or do not carry the trait can be important when it comes to planning a family.

How Can I Know If I Carry The Trait?

There are screening tests that can tell whether or not you have thalassemia trait. The initial test involves a few drops of blood from your fingertip to determine if there are any problems with your blood. If anything abnormal is detected, another test called *Hemoglobin Electrophoresis* can be done. This test requires a



small sample of blood from a vein and is used to confirm the diagnosis.

What Can You Do to Minimize the Concern About Thalassemia?

1 You can find out more about thalassemia. You can learn what it is, who is affected by it, and why screening is important. Ask your doctor or health center about this.

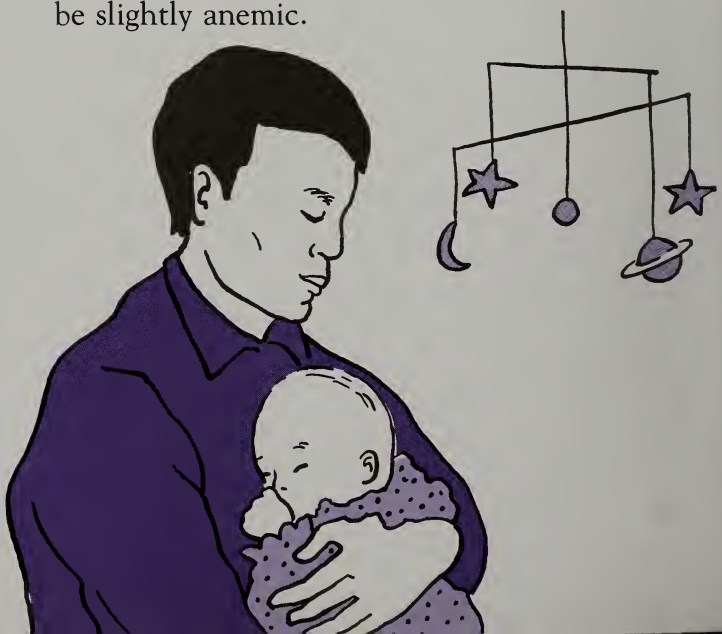
2 You can be screened for the thalassemia trait. You can find out if you are a carrier of the trait and if other family members are carriers.

3 For couples that are both identified as having thalassemia trait, genetic counseling can provide information on the possibility of risk in any pregnancy.

4 Screening your newborn baby for beta thalassemia will enable early detection. Once diagnosed, your newborn can receive early treatment and better care.

Some Important Facts to Keep in Mind About Thalassemia

- Thalassemia is an inherited blood disorder, which means it can be passed down through generations.
- There is a high prevalence of thalessemia among Asians, especially Southeast Asians.
- Being a trait carrier of the disease means you are not affected, but carry a gene for the disease. You will live a normal and healthy life but may be slightly anemic.



- If two carriers decide to have children, there is a possibility that they could pass a thalassemia gene to the unborn baby, the baby will then have the disease thalassemia.
- There are blood tests that can tell you whether or not you are a trait carrier of thalassemia. By finding out if you and your spouse are carriers, you will be able to make effective decisions regarding family planning.
- Most forms of thalassemia can be treated. Knowing your baby has thalassemia can save his or her life. Early diagnosis is very crucial.

Whom Should I Contact if I Want More Information?

Thalassemia is a disease that has been found most common in the Asian community (especially Southeast Asian). Finding out more about this disease can help protect you and your family. If you would like more information about thalassemia, contact your local doctor or health center. You may also want to talk to them about being screened for the thalassemia trait.

This brochure is available in English, Chinese, Korean, Laotian, Tagalog and Vietnamese.

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Illustrated by Ellen Joy Sasaki
Designed by Peter Matsukawa